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Influence of burden, stress and depressive symptoms on the health of older adult caregivers: a longitudinal study

Influência da sobrecarga, estresse e sintomas depressivos na saúde de idosos cuidadores: estudo longitudinal

Influencia de la carga, el estrés y los síntomas depresivos en la salud de los cuidadores de personas mayores: un estudio longitudinal

Marielli Terassi[1]
Sirlei Ricarte Bento[1]
Estefani Serafim Rossetti[1]
Sofia Cristina Iost Pavarini[1]
Priscilla Hortense[1]

1. Universidade Federal de São Carlos.
São Carlos, SP, Brasil.

Abstract

Objective: to analyze the effect of burden, stress, and depressive symptoms on the health characteristics of older adult caregivers of older adults. **Method**: A quantitative and longitudinal study was conducted with 127 older adult caregivers to analyze the effect of burden, stress, and depressive symptoms on their health characteristics. The variables assessed included health characterization, burden, depressive symptoms, and stress. A linear regression model and Poisson test were employed, with a significance level set at 5%. **Results**: The findings revealed that an increase of one point in the burden scale score was associated with a 0.030 increase in the number of diseases (p=0.020) and an increased risk of chronic pain (p=0.005). Similarly, a one-point increase in the stress scale score was associated with a 0.058 increase in the number of diseases (p=0.001), as well as an increased risk of a poor subjective health assessment (p=<0.001) and chronic pain (p=<0.001). Furthermore, an increase in the score on the depressive symptoms scale was associated with an increase in the number of diseases (p=<0.001), risk of falls (p=0.009), poor subjective health assessment (p=<0.001), and chronic pain (p=<0.001). **Conclusions and implications for practice**: The worsening estimate in the scores of psychological variables poses a risk to the deterioration of caregivers' physical health characteristics. The findings underscore the need for the development of public policies aimed at improving the quality of life for older adult caregivers.

Keywords: Caregivers; Depression; Stress, Elderly; Psychological.

Resumo

Objetivo: analisar o efeito da sobrecarga, do estresse e dos sintomas depressivos sobre as características de saúde de idosos cuidadores de idosos. **Métodos:** estudo quantitativo e longitudinal com 127 idosos cuidadores. As variáveis utilizadas foram caracterização de saúde; sobrecarga; sintomas depressivos e estresse. Realizou-se modelo de regressão linear, teste de Poisson, com nível de significância de 5%. **Resultados:** observou-se que um ponto a mais no escore na escala de sobrecarga aumenta em 0,030 o número de doenças (p=0,020) e risco de dor crônica (p=0,005); um ponto a mais no escore na escala de estresse aumenta em 0,058 o número de doenças (p=0,001) e risco para avaliação de saúde regular/ruim (p=<0,001) e dor crônica (p=<0,001); o aumento no escore na escala de sintomas depressivos aumenta o número de doenças (p=<0,001), risco de quedas (p=0,009), avaliação de saúde regular/ruim (p=<0,001) e dor crônica (p=<0,001). **Conclusões e implicações para a prática:** estimativa de piora nos escores das variáveis psicológicas acarreta um risco para o agravamento de características de saúde física dos cuidadores. Com os resultados encontrados, observar-se a necessidade da criação de políticas públicas para os idosos cuidadores, a fim de propiciar uma melhor qualidade de vida.

Palavras-chave: Cuidadores; Depressão; Estresse Psicológico; Idoso.

Resumen

Objetivo: analizar el efecto de la sobrecarga, el estrés y los síntomas depresivos sobre las características de salud de los cuidadores de ancianos. **Métodos**: estudio cuantitativo y longitudinal con 127 cuidadores de ancianos. Las variables utilizadas fueron caracterización de la salud; sobrecarga; Síntomas depresivos y estrés. Se realizó un modelo de regresión lineal, prueba de Poisson, con un nivel de significancia del 5%. **Resultados**: se observó que un punto más en la puntuación de la escala de sobrecarga aumenta en 0,030 el número de enfermedades (p=0,020) y el riesgo de dolor crónico (p=0,005); un punto más en la puntuación de la escala de estrés aumenta en 0,058 el número de enfermedades (p=0,001) y el riesgo de evaluar regular/mala salud (p=<0,001) y dolor crónico (p=<0,001); el aumento de la puntuación en la escala de síntomas depresivos aumenta el número de enfermedades (p=<0,001), riesgo de caídas (p=0,009), valoración regular/mala de la salud (p=<0,001) y dolor crónico (p=<0,001). **Conclusiones e implicaciones para la práctica**: la estimación del empeoramiento de las puntuaciones de las variables psicológicas conlleva un riesgo de empeoramiento de las características de salud física de los cuidadores. Con los resultados encontrados, se evidencia la necesidad de crear políticas públicas para los cuidadores de adultos mayores, con el fin de brindarles una mejor calidad de vida.

Palavras-clave: Ancianos; Cuidadores; Depresión; Estrés Psicológico.

Corresponding author:
Marielli Terassi.
E-mail: ma_terassi@hotmail.com

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INTRODUCTION

The increase in life expectancy and the reduction in birth and mortality rates, lead to a globally recognized phenomenon, population aging, which brings about a scenario with high demand for care due to the increased morbidity in the older adult population, particularly regarding Noncommunicable Chronic Diseases (NCDs).[1-4]

The profile of the older adult caregiver is characterized as informal, predominantly carried out by females, most often spouses or daughters.[2,5,6] Due to longevity, demographic changes, and family structure, a new scenario that is increasingly frequent is that of older adults serving as caregivers, which is a concerning fact since health complications tend to occur due to advancing age.[2,3,5,7] Engaging in the caregiving task involves providing frequent assistance for activities of daily living and for health maintenance/recovery, demanding skills that informal caregivers are often not trained to perform, making the tasks more overloading and contributing to increased caregiver burden and stress.[3,8]

Research indicates health impairments resulting from the burden associated with caregiving. A study was conducted in the United States with the objective of assessing the association between caregiver burden and the propensity for developing physical symptoms among older adult caregivers. It found that participants with greater burden were more likely to experience physical symptoms such as pain, decreased lower limb strength, and feelings of low energy.[9] Other studies also demonstrate that psychological stress, physical impairment, and health problems in caregivers are related to burden associated with the caregiving task,[10,11] and the health consequences can be even more severe when the caregiver is also an older adult.

Longitudinal analyses on how health characteristics and other variables behave in older adult caregivers of older adults in Brazil are identified as a gap in the literature. Considering the increase in older adult caregivers of older adults, longitudinal studies become essential to develop more targeted actions aimed at preventing future health impairments in this population.

Cross-sectional studies indicate psychological complications associated with the act of caregiving in older adult caregivers. A cross-sectional study conducted with 202 older adult caregivers aimed to investigate the factors associated with depression in caregivers, identifying that increased hours spent on caregiving and higher levels of neuroticism were associated with depressive symptoms in the investigated population.[12] In Spain, a study conducted with a sample of 200 caregivers with a mean age of 59.8 years found that 37% reported depressive symptoms. The psychological burden was related to social pressure to provide care, further increasing the caregiving burden. The authors emphasized the importance of early detection of the negative impact of caregiving as a means to prevent impairments such as depression.[4]

Caregivers who neglect their own health to care for others become doubly vulnerable when their health problems are added to the burden of caregiving demands,[2,13,14] which can result in difficulties in providing care and increased burden on the public healthcare system. Given the aforementioned factors and the scarcity of research in the literature on this topic, the present study aimed to analyze the health conditions of older adult caregivers of older adults over time in a Brazilian sample. The expectation is to contribute to the development of future health and well-being policies and programs with the aim of providing adequate assistance, thus avoiding greater burdens on public health.

Therefore, the present study aimed to analyze the effects of burden, stress, and depressive symptoms on the health characteristics of older adult caregivers of older adults.

METHOD

This was a quantitative longitudinal study[15], guided by the STROBE guidelines, with two assessments within a four-year interval. Data collection took place in the city of São Carlos, SP, Brazil, between 2014 and 2018.

The sample was defined based on the first assessment, which took place from April to November 2014, including 15 Family Health Units (FHUs) in the urban area of the municipality. Participants were identified through lists provided by the FHUs containing the names and addresses of older adults residing with another older adult. Researchers contacted the FHUs in advance to obtain the addresses, and all households where two or more older adults resided were visited by the researchers.

In the first assessment (2014), 266 older adult caregivers who met the following inclusion criteria participated in the study: aged 60 or older, residing in the urban area of São Carlos, registered in one of the FHUs, and providing informal care to another older adult in the same household. Older adults who were not found at home after three attempts, cases of death, change of address, refusal to participate, and situations where both older adults were equally independent in activities of daily living were excluded.

To identify the older adult caregiver, questionnaires assessing performance in basic activities of daily living[16] and instrumental activities of daily living[17] were used. The older adult with the better performance in the sum of the scores from both instruments was considered the caregiver, while the older adult with the lower score was the care recipient.[5] When both older adults obtained the same score and were independent in all activities, they were excluded from the study.

In the second assessment in 2018, all households were visited again, as described in a previous study.[18] Loss to follow-up occurred due to the death of the caregiver or care recipient (n=32), three unsuccessful contact attempts on different days and times (n=16), change of address (n=36), refusals (n=46), and significant speech impairment or cognitive decline preventing assessment by the interviewer (n=9). The Addenbrooke's Cognitive Examination Revised (ACE-R)[19] was used to assess cognitive decline. Older adults with severe impairment, i.e., unable to respond to the instrument, were excluded from the study.

Thus, the final sample of the present study consisted of 127 participants. Figure 1 presents the flowchart of participants included and excluded in 2014 and 2018.

In both assessments, information on sociodemographic and health characteristics, as well as psychosocial variables (caregiver burden, depressive symptoms, and perceived stress), was collected. For the collection of sociodemographic and health data, an instrument was used that included information on gender (male/female), age (in years), education (in years), number of medications, number of comorbidities, subjective health assessment (good or fair/poor), presence of pain (yes/no), falls in the last 12 months (yes/no), and daily hours dedicated to caregiving. These data were self-reported by the participants.

Chronic pain was defined as pain lasting six months or longer, of continuous or recurrent nature, affecting any body region, and assessed for intensity using an 11-point Numeric Rating Scale (0-10), with 0 representing no pain and 10 representing the worst imaginable pain.[20]

The Zarit Burden Interview with 22 Likert-type questions was used to assess caregiver burden. The sum of the questions can range from 0 to 88 points, with higher scores indicating greater burden.[21]

Depressive symptoms were assessed using the Geriatric Depression Scale (GDS-15), which aims to screen for depressive symptoms in older adults. Scores can range from 0 to 15 points, with scores higher than 5 suggesting the presence of depressive symptoms.[22]

Perceived stress was assessed using the Perceived Stress Scale (PSS), consisting of 14 questions and a total score ranging from 0 to 56.[23] The scale does not have a cutoff score; higher scores indicate higher levels of stress.

For data analysis, a database was created without individual identification in Excel 2016 software. After double-entry validation by the same researcher, the data were exported to SAS system for Windows (9.2) software.

For comparisons involving quantitative variables (number of medications, number of diseases, burden, stress, and depressive symptoms) and differences between time points (2014 and 2018), a linear regression model with mixed effects (random and fixed effects) was proposed. The Poisson test with simple and multiple robust variance was used in the analyses of qualitative variables (falls in the last 12 months, subjective health assessment, and presence of chronic pain) to estimate the relative risk (RR). All models were adjusted for gender, age, and education. A significance level of $p \leq 0.05$ was considered.

The present study received authorization from the Municipal Health Secretary and the Research Ethics Committee with Human Subjects for the data collection conducted in 2014 (CAAE: 22956313.6.0000.5504) and for the 2018 data collection (CAAE: 90749218.4.0000.5504). The ethical aspects contained in Resolution 466/2012 CNS were respected. All older adults who agreed to participate in the study signed the Informed Consent Form.

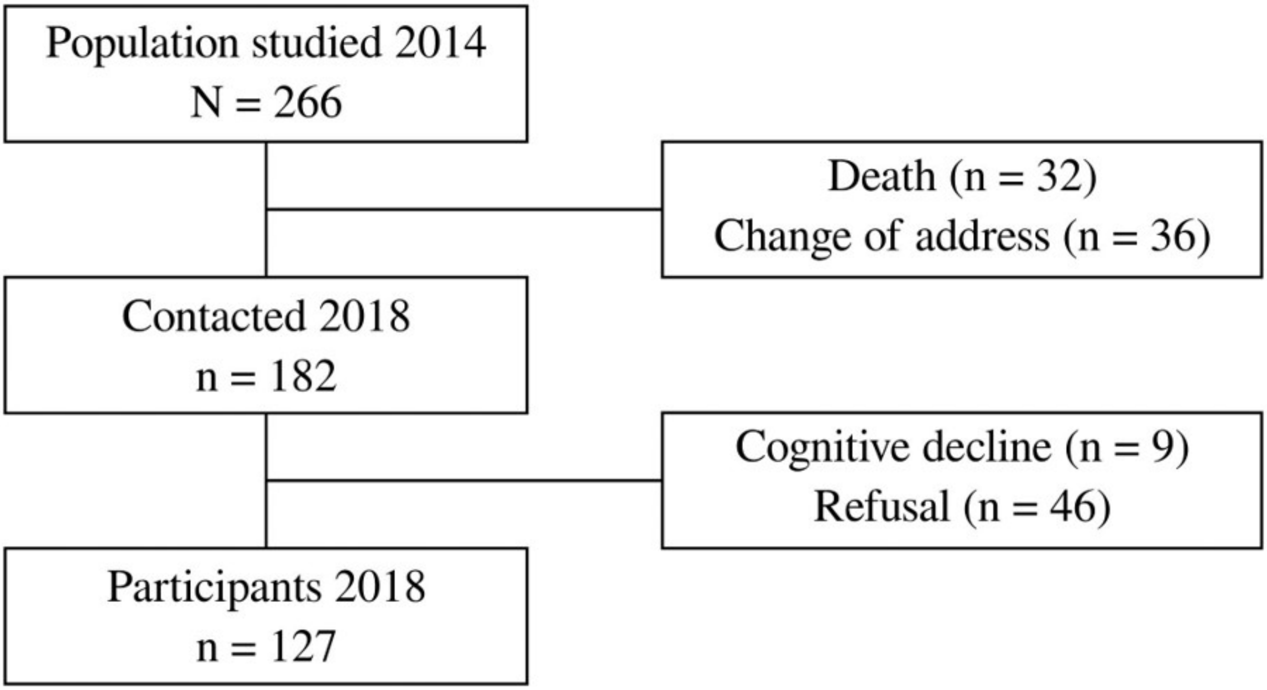

Figure 1. Flowchart of participants included and excluded from the study. São Carlos, 2018.
Source: developed by the authors.

RESULTS

A total of 127 older adult caregivers participated in the study, with a mean age of 68.2 (±1.7) years, a predominance of females (78.7%), and a mean education of 3.3 (±3.1) years. Regarding caregiving characteristics, the majority of participants provided care to their spouse (85%), for a mean duration of 9.2 years in 2014, and spent a mean of 5.4 hours per day performing these caregiving tasks. Table 1 presents the descriptive data related to health characteristics, burden, stress, and depressive symptoms over a four-year period.

Table 2 presents the results of the health characteristics and the variables burden, stress, and depressive symptoms in relation to the longitudinal assessment, aiming to determine the effect of time on these variables. It was observed that the number of medications used by older adults increased over time, with evidence of a difference (-0.427, p=0.028). In contrast, the variables number of diseases (0.802; p=0.028), burden (7.674; p=0.001), and depressive symptoms (0.737; p=0.002) decreased over time.

In Table 3, the effect of the variables burden, depressive symptoms, and perceived stress on health characteristics over time was examined. For each increase of one point in the burden score, the number of diseases increased by 0.030 (p=0.020), and the risk of individuals experiencing chronic pain increased (RR=1.009; p=0.005). Regarding stress, for each increase of one point in the score of this variable, the number of diseases increased by 0.058 (p=0.001), and the risk of having a fair/poor subjective health assessment increased (RR=1.029; p=<0.001), as well as the risk of chronic pain presence (RR=1.020; p=<0.001). It was also observed that higher scores in depressive symptoms increased the number of diseases (p=<0.001), the risk of falls (RR=1.080; p=0.009), the risk of a fair/poor subjective health assessment (RR=1.135; p=<0.001), and the risk of chronic pain presence (RR=1.089; p=<0.001).

Table 1 - Health characteristics, burden, stress, and depressive symptoms of older adult caregivers (N=127). São Carlos, SP, Brazil 2014 - 2018.

Variables	2014	2018
Number of medications	3.1 ± 2.19	3.6 ± 2.44
Number of diseases	4.9 ± 3.11	4.1 ± 2.45
Presence of falls	42 (33.07%)	31 (24.41%)
Subjective evaluation of health	Good: 72 (51.43%) Regular/Poor: 55 (48.67%)	Good: 58 (51.33%) Regular/Poor: 68 (48.57%)
Presence of chronic pain	76 (48.1%)	82 (51.9%)
Stress (mean; SD)	19.6 ± 10.49	20.3 ± 9.83
Depressive symptoms (mean; SD)	3.8 ± 2.85	3.1 ± 2.75
Caregiver burden (mean; SD)	18.7 ± 15.12	11.23 ± 12.3

Source: developed by the authors.

Table 2 - Analysis of the effect of time on health characteristics, burden, stress, and depressive symptoms of older adult caregivers (N = 127) over a four-year period. São Carlos, SP, Brazil, 2014-2018.

Variables	Difference estimate*	Relative risk*	95%CI†		P value
Number of Medications	-0.427		-0.807	-0.047	**0.028‡**
Number of Diseases	0.802		0.351	1.256	**0.001‡**
Falls in the Last 12 Months		1.355	0.926	1.983	0.118 §
Subjective Assessment (Good/Regular or Poor)		0.945	0.775	1.152	0.574§
Presence of Chronic Pain		0.918	0.808	1.043	0.189§
Caregiver Burden	7.674		3.489	11.860	**0.001‡**
Stress	-0.691		-2.569	1.188	0.468‡
Depressive Symptoms	0.737		0.274	1.200	**0.002‡**

Source: developed by the authors
* Analysis conducted with data from 2014 versus 2018; † 95% CI Confidence Interval; ‡ Linear regression with mixed effects (random and fixed effects); § Poisson test with robust variance; Model adjusted for gender, age, and education.

Table 3 - Analysis of the effect of burden, stress, and depressive symptoms on health characteristics of older adult caregivers (N=127) over a four-year period. São Carlos, SP, Brazil, 2014-2018.

Variables	Difference estimate*	Relative risk*	95%CI[†]		P value
Number of Medications					
Caregiver Burden	-0.006		-0.028	0.016	0.573[‡]
Stress	0.022		-0.006	0.050	0.126[‡]
Depressive Symptoms	0.127		0.021	- 0.232	0.232[‡]
Number of Diseases					
Caregiver Burden	0.030		0.005	0.055	**0.020[‡]**
Stress	0.058		0.024	0.091	**0.001[‡]**
Depressive Symptoms	0.267		0.144	0.389	**<0.001[‡]**
Falls in the Last 12 Months					
Caregiver Burden		1.188	0.743	1.901	0.472[§]
Stress		1.395	0.090	0.950	0.090[§]
Depressive Symptoms		1.080	1.019	1.144	**0.009[§]**
Subjective Health Assessment					
Caregiver Burden		0.862	0.656	1.132	0.286[§]
Stress		1.029	1.016	- 1.041	**<0.001[§]**
Depressive Symptoms		1.135	1.093	1.178	**<0.001[§]**
Presence of Chronic Pain					
Caregiver Burden		1.009	1.003	1.016	**0.005[§]**
Stress		1.020	1.011	-1.030	**<0.001[§]**
Depressive Symptoms		1.089	1.059	1.120	**<0.001[§]**

Source: developed by the authors
* Analysis conducted with data from 2014 versus 2018; † 95% CI - 95% Confidence Interval; ‡ Linear regression with mixed effects (random and fixed effects); § Poisson test with robust variance. Model adjusted for gender, age, education.

DISCUSSION

In the present study, the influence of psychological variables on health characteristics was observed over four years, with an association between increases in burden scores and an increase in the number of diseases and risk for the presence of chronic pain. In the assessment of stress, an increase in this variable's score was associated with an increase in the number of diseases and a higher risk for subjective evaluation of fair/poor health and presence of chronic pain. An increase in depressive symptoms also increased the number of diseases, the risk of falls, evaluation of fair/poor health, and the presence of chronic pain.

When comparing the variables during the years 2014 and 2018, the results show that the number of medications showed an estimated increase over the four years. However, in the variables burden, depressive symptoms, and number of diseases, it was possible to identify a reduction in scores after four years. For the other variables, there were no significant changes in the period.

The increase in the number of medications may be associated with polypharmacy, which is frequent in this population.[24] Data similar to those of the present study were found in a 16-month follow-up study conducted in Belgium with caregivers over 70 years of age, in which the authors observed an increase in the number of medications used in the second evaluation, mainly anxiolytics.[25]

A longitudinal study conducted in Finland with a sample of informal caregivers with a mean age of 66 years (±10.2) caring for people with Alzheimer's pointed to a significant increase in the mean number and proportion of medications used in the previous five years. These authors also presented as a result the comparison between the agreement between the self-reported data and medical prescription records, revealing a significant increase in self-medication.[26] A study conducted with caregivers of older adults with dementia found that access to the care receiver's medication facilitated the use of inappropriate medication, and among the medications most used by caregivers, they mentioned oral estrogens, benzodiazepines, fluoxetine, muscle relaxants, among others.[27]

In the present study, participants presented a lower score for depressive symptoms in the second evaluation, a fact that corroborates with an English longitudinal study conducted with caregivers over the age of 50. The study demonstrated a decrease in the mean scores of depressive symptoms of participants who provided continuous care for a period of two years.[28] Conversely, a study conducted in China between the years 2011-2015 evaluated a group of caregivers and non-caregivers, observing that participants who started providing care during this period had higher levels of depressive symptoms compared to participants who did not provide care.[29]

The influence of caregiving on psychological variables may change over time, due to positive and negative factors associated with the care. However, after adapting to social changes in the caregiver's life, feelings such as gratitude and the perception of helping a family member contribute to reducing negative feelings associated with care and may positively affect psychological variables and life satisfaction.[30]

Regarding the reduction in burden scores over time found in this study, it is believed that caregivers' adaptations associated with care and related to feelings of gratitude and resilience[30,31] may have contributed to lower burden scores in the second evaluation. A systematic review in the period from 2009 to 2019 showed that adaptation to the routine of care activities occurs due to resilient coping, which reduces the risk factors for emotional harm in informal caregivers.[31] Similar data were observed in a longitudinal study conducted with Japanese caregivers, in which, over a period of one year, there was no evidence of an increase in burden, as the caregivers showed a decrease in the score on the scale referring to personal tension faced with care activities.[32]

Regarding the influence of the variables burden, stress, and depressive symptoms on health characteristics over four years, an increase in burden scores was associated with a higher number of diseases and chronic pain. Burden is considered to be an important variable by some authors, which assists in assessing the health of caregivers and the characteristics of the care provided.[33]

Although long-term studies with a sample of older adult caregivers are scarce, national and international research highlights that high levels of burden can contribute to a worsening of physical and psychological health in caregivers, causing fatigue, sleep disorders, loss of attention, presence of pains and increase in comorbidities.[33-34] Furthermore, chronic pain can imply a major impact on the life of the older adult, showing an increase in intensity with advancing age, a negative influence on quality of life, and a reduction in the functionality of the person.[35] It is emphasized that the presence of pain contributes to the worsening of the burden and difficulties in performing care activities.[36]

In Japan, a cross-sectional study with a sample of 156 caregivers with a mean age of 65 years (±10.4), an association was reported between lower back pain and the activities developed in the act of caregiving. It was observed that 70% of the sample referred to psychological stress, and this percentage increases to 85.7% among caregivers with reports of pain, making it difficult to perform care activities and reducing caregivers' quality of life.[37]

In the present study, it was possible to verify that over four years, an increase in depressive symptom indices generated a greater number of diseases, risk of falls, evaluation of fair/poor health, and chronic pain. Corroborating these results, a cross-sectional study conducted in Florianopolis with 1656 older adults observed that depressive symptoms were associated with the occurrence of falls in the last year, report of pain and worse perception of health.[38] A study conducted with 202 caregivers over the age of 55 in Australia observed a correlation between the number of medications and depressive symptoms, data that were not evidenced in the present study.[39]

The complications resulting from caregiving can be greater depending on the degree of dependence of the care receiver.[40,41] In a cross-sectional study with informal caregivers of people with dementia over the age of 21, investigators in the southern part of the southwestern United States demonstrated a significant link between chronic diseases, caregiver age, and sex. The risk of chronic diseases was almost three times higher for caregivers over 65 years of age, compared to those under 65.[42] In this context, data from a study conducted in the State of Sao Paulo with 362 caregivers showed that the excessive tension of caregivers for older adults was associated with continuous care, family dysfunction, age, and the functional and cognitive conditions of the cared-for older adult.[6]

These results demonstrate the importance of health care focused on promoting the psychological well-being of older adult caregivers, as most informal caregivers do not have support or assistance focused on the risk of physical and psychological exhaustion triggered by the act of caregiving. Thus, the need for evaluation actions and new studies focused on this population is highlighted. Longitudinal studies on the health of older adult caregivers are certainly necessary and should be deepened, just as the actions developed by Family Health Units should be strengthened and encouraged with the aim of improving health care provided to the older adult caregiver and care receiver.

The results obtained from this study can contribute to a better understanding of health conditions over the years of older adults caring for older adults, supporting the professional practice in the development of activities of comprehensive care for the older adult caregiver. This study also helps raise awareness among healthcare providers about the importance of early detection of health issues and providing appropriate interventions for a population that prioritizes care for another older adult over their own well-being. Health interventions conducted individually or in groups with older adult caregivers, aimed at promoting physical and psychological well-being, such as workshops, exercises, and group discussions, can contribute to healthcare assistance for this population.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The results demonstrated that only the variable "number of medications" showed an estimated increase over the four years, while caregiver burden scores, depressive symptoms, and number of diseases showed a reduction.

It was found that an increase in the scores of psychological variables poses a risk for the exacerbation of certain variables associated with the physical health of older adult caregivers. Caregiver burden showed an association with the number of diseases and the risk of chronic pain. Stress was associated with an increased number of diseases, subjective evaluation of regular/poor health, and the presence of chronic pain. Depressive symptoms were related to an increase in the number of diseases, falls, subjective evaluation of regular/poor health, and the presence of chronic pain.

Although this study has yielded interesting results regarding the health of older adult caregivers, some limitations should be noted. Unfortunately, there was a significant reduction in the number of participants in the second assessment (n=127). The variable "number of diseases" was obtained through self-reporting, which may introduce bias in the data. Information about the health of the care recipients was not collected, which could have helped in understanding the results obtained. Similarly, data on sleep quality and physical activity of the caregiver should be considered in future studies, as these factors can interfere with the physical and psychological health of older adult caregivers.

Based on the findings, there is a need to establish public policies for older adult caregivers in order to improve their quality of life and contribute to the implementation of actions that focus on their physical and psychological well-being.

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AUTHOR'S CONTRIBUTIONS

Study design. Marielli Terassi. Sirlei Ricarte Bento. Estefani Serafim Rossetti. Sofia Cristina Iost Pavarini. Priscilla Hortense.

Data collection: Marielli Terassi. Sirlei Ricarte Bento. Estefani Serafim Rossetti. Sofia Cristina Iost Pavarini.

Data analysis and interpretation of results. Marielli Terassi. Sofia Cristina Iost Pavarini. Priscilla Hortense.

Article writing and critical review. Marielli Terassi. Sirlei Ricarte Bento. Estefani Serafim Rossetti. Sofia Cristina Iost Pavarini. Priscilla Hortense.

Approval of the final version of the article. Marielli Terassi. Sirlei Ricarte Bento. Estefani Serafim Rossetti. Sofia Cristina Iost Pavarini. Priscilla Hortense.

Responsibility for all aspects of the content and the integrity of the published article. Marielli Terassi. Sirlei Ricarte Bento. Estefani Serafim Rossetti. Sofia Cristina Iost Pavarini. Priscilla Hortense.

ASSOCIATED EDITOR

Cristina Lavareda Baixinho

SCIENTIFIC EDITOR

Marcelle Miranda da Silva

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